Establishing an Advisory Group

Patients, parents, and other family members will bring new ideas and relevance to any medical education curriculum. This chapter describes practical steps to begin an advisory group and develop new activities for the curriculum in a medical school or residency program. To begin partnering with these important contributors, the first step is to invite a group of advisors to plan a new activity targeted to an important competency.

Inviting parents, patients, and family members to participate in planning and implementing medical education requires a slight shift in orientation, perspective, approach, and vocabulary. These valuable partners bring insights from experience rather than from formal training. The words they use to describe their insights do not incorporate formal educational vocabulary. When educators discuss competencies, curriculum objectives, and requirements of the Liaison Committee on Medical Education or the Accreditation Council on Graduate Medical Education, their vocabulary will not communicate to patients and families the concepts shared and assumed by trained medical educators. To make the medical education environment accessible to these less traditional partners, we need a more colloquial vocabulary and an open mind. This chapter uses a less formal vocabulary than the first two chapters in an attempt to convey a tone that facilitates collaborative work with patients and families while describing the process of establishing an advisory group.

"A good physician knows the algorithms and the diagnoses. A good physician also sees the human struggle."

–a parent-advisor

Start with Competencies that Parents or Patients can Address

Medical educators plan curricula to address requirements that have been set by professional organizations or educational experts. We all need a broad array of ideas and useful content to address these competencies and patient- and parent-advisors can help. One easy way to begin is to look through a set of competencies and identify those for

"I think it's terrific for doctors to understand the family in context … Our story is in human terms as opposed to medical terms."
–a parent-advisor

which a patient, parent, or other family member might have important insight because of the perspective from which they experience medical care. For example, when reading through the Accreditation Council on Graduate Medical Education (ACGME) competencies, you might notice that patients and family members have important experience that would help medical students and residents understand how to apply the following sets of skills:

ACGME GENERAL COMPETENCIES Vers. 1.3G[1]

(EXCERPT THAT PARENT AND PATIENT ADVISORS MAY INFORM)

[P]rograms must define the specific knowledge, skills, and attitudes required and provide educational experiences as needed in order for their residents to demonstrate the competencies.

PATIENT CARE

Residents must be able to provide patient care that is compassionate, appropriate, and effective for the treatment of health problems and the promotion of health. Residents are expected to:

- Communicate effectively and demonstrate caring and respectful behaviors when interacting with patients and their families.
- Gather essential and accurate information about their patients.
- Make informed decisions about diagnostic and therapeutic interventions based on patient information and preferences, up-to-date scientific evidence, and clinical judgment.
- Develop and carry out patient management plans.
- Counsel and educate patients and their families.
- Use information technology to support patient care decisions and patient education.

INTERPERSONAL AND COMMUNICATION SKILLS

Residents must be able to demonstrate interpersonal and communication skills that result in effective information exchange and teaming with patients, their patients' families, and professional associates. Residents are expected to:

- Create and sustain a therapeutic and ethically sound relationship with patients.
- Use effective listening skills and elicit and provide information using effective nonverbal, explanatory, questioning, and writing skills.

PROFESSIONALISM

Residents must demonstrate a commitment to carrying out professional responsibilities, adherence to ethical principles, and sensitivity to a diverse patient population. Residents are expected to:

- Demonstrate respect, compassion, and integrity; a responsiveness to the needs of patients and society that supercedes self-interest; accountability to patients, society, and the profession; and a commitment to excellence and on-going professional development.
- Demonstrate a commitment to ethical principles pertaining to provision or withholding of clinical care, confidentiality of patient information, informed consent, and business practices.
- Demonstrate sensitivity and responsiveness to patients' culture, age, gender, and disabilities.

SYSTEMS-BASED PRACTICE

Residents must demonstrate an awareness of and responsiveness to the larger context and system of health care and the ability to effectively call on system resources to provide care that is of optimal value. Residents are expected to:

- Advocate for quality patient care and assist patients in dealing with system complexities.

(Full set of competencies Copyright 2001 ACGME)

In developing a way to teach any of these competencies, having the insight of the patients and families who experience physicians' care, communication, and relationships leads to education that equips students and residents to meet patients' needs more effectively.

"Professionalism in medicine requires the physician to serve the interests of the patient above his or her self interest."
–American Board of Internal Medicine, 1995, *Project Professionalism*

A group of patients and family members begins to generate useful ideas for medical education when asked clear, specific questions that relate to their own experience.

Think of Clear, Specific Questions that Patients and Family Members can Answer

A group of patients and family members begins to generate useful ideas for medical education when asked clear, specific questions that relate to their own experience. When considering the ACGME competencies, the following sample questions for focus groups come to mind:

Competency	*Questions for Advisors*
PATIENT CARE Residents must be able to provide patient care that is compassionate...	What can a physician do to express compassion? Think about a physician who has been especially compassionate. What did he or she do that made you feel like they cared?
Residents are expected to: • Communicate effectively and demonstrate caring and respectful behaviors when interacting with patients and their families.	What does it look like when a physician respects you? When a physician communicates effectively with your child, what does he or she do? Think about a recent time when a physician explained something very complicated to you. What did that physician do to help you understand? Has a physician ever had to tell you very bad news? What did that physician do that you especially appreciated? What did you not appreciate?

Competency	*Questions for Advisors*
PATIENT CARE Residents are expected to: • Gather essential and accurate information about their patients.	How do you know if a physician understands what you are trying to explain? When you go to the doctor and you know something is terribly wrong but you're not sure what it is, what can that doctor do to help you explain the problem? When your child is sick, how can a physician help you explain all the important details?
Residents are expected to: • Make informed decisions about diagnostic and therapeutic interventions based on patient information and preferences...	Think of a time when you had to make a decision about whether to take a certain medication or have a medical procedure done. What did you want the physician to know about your values, preferences, and life?
Residents are expected to: • Develop and carry out patient management plans.	Explain a treatment that was hard for you to follow through on. Maybe it was surgery you didn't want to have, or a medication plan for your child that was very inconvenient. Did you do it? Why or why not? What did the physician do to help you decide what to do? Did you and the physician come up with a plan together? If so, how did the physician help you participate in developing the plan?

"Despite rhetoric about increasing partnership in the consultation, shared decision making (SDM) is not necessarily happening in practice."
–Fiona Stevenson, 2003,
Patient Education and Counseling

"Medical education must seek to promote the moral development of its students. Medicine, after all, is a moral profession."

–William Branch, 2000, *Journal of General Internal Medicine*

Competency	*Questions for Advisors*
PATIENT CARE Residents are expected to: • Counsel and educate patients and their families.	Think of a time when you received a new diagnosis for you, your child, or another member of your family. What information did you need from the physician about that diagnosis and what it meant? How did the physician explain it so it made sense to you? Or, what could the physician have done to communicate more clearly?
INTERPERSONAL AND COMMUNICATION SKILLS Residents must be able to demonstrate interpersonal and communication skills that result in effective information exchange and teaming with patients, their patients' families, and professional associates. Residents are expected to: • Create and sustain a therapeutic and ethically sound relationship with patients. • Use effective listening skills and elicit and provide information using effective nonverbal, explanatory, questioning, and writing skills.	How can you tell if a physician is listening to you? What happens when you develop a good relationship with a physician? What difference does your relationship with your physicians make in your care and healing? What does it mean to have an ethically sound relationship with a physician?

Competency	*Questions for Advisors*
PROFESSIONALISM	What does professionalism in medicine mean to you as a patient? Sometimes we think about the relationship of trust between physicians as a group and the people in our society as a group. How strong do you think this relationship of trust is today? What have your own physicians done to build this trust? What have they done to make it harder for you to trust physicians?
SYSTEMS-BASED PRACTICE Residents are expected to: • Advocate for quality patient care and assist patients in dealing with system complexities.	What does it look like when a physician advocates for you? What makes it hard for you to get the care you need in the healthcare system? What do you need from your physician to make your insurance plan work for you?

"I hope that [talking] with parents can make it a little more real. We need doctors to have a combination of empathy and steadiness about their professionalism."

–a parent-advisor

Consider the Educational Context

The insights of patients and families in regard to questions like those above can contribute to medical education and to an understanding of the relationship between patients and physicians. The next point to consider is the needs and opportunities of a specific educational setting. Where in that setting might there be opportunities to try a new activity and involve some patients or families in the planning, teaching, or evaluation? Each educational setting reflects different circumstances, so the opportunities will be unique to each curriculum and educational environment. For example, we first got started when a curriculum reform committee was exploring the feasibility of integrating more clinical ex-

Any time a faculty member wants to try something new and the content of the teaching has something to do with communication, patient-doctor relationships, professionalism, or how patients and families are affected by health care, there is an opportunity for patient- and family-advisors to contribute useful insights.

periences in the first two years of medical school. A pediatrician on the committee asked if we could gather a group of parents to find out what they thought we should teach medical students about how to interact with parents and children. Another opportunity emerged when the Family Medicine faculty was developing a new curriculum for the Family Medicine Clerkship and expressed interest in teaching about how to advocate for patients and families. A third opportunity arose over lunch with the course director for bioethics. He asked, "What might happen if enough parents came to the opening session of the ethics course to meet with small groups of students to tell the stories of their children's time in newborn intensive care?" Any time a faculty member wants to try something new and the content of the teaching has something to do with communication, patient-physician relationships, professionalism, or how patients and families are affected by health care, there is an opportunity for patient- and family-advisors to contribute useful insights.

Several educational venues provide good opportunities for patients and families to share their perspectives with medical students and residents. Home visits with explicit goals provide the most obvious natural setting for patients and families to tell the stories of their healthcare experiences and how they have affected their lives. Small group discussions in which one or two people share their experiences as patients also work well. Occasional presentations to large groups by someone with experience as a patient or family member can be effective, but this venue tends to be less comfortable for many patient-and family-advisors and provides little opportunity for the students or residents to ask questions and interact directly with the person whose experience they are trying to understand. Large group presentations also run the risk of looking like the person is "on display" as a patient rather than a real person telling a story about his or her life or a collaborator who has insights to share that make medical education more relevant and useful.

Find Roles for Patient- and Family-Advisors

The easiest way to begin is with a focus group of people with experiences as patients or parents. After meeting in a focus group once or twice, a few group members may express interest in becoming more involved in medical education. They can form a work group to accomplish a spe-

cific curricular task, such as to help plan a home visit program for the Pediatric Clerkship or residency, help refine a research question, or draft items for an evaluation survey. Once you have a few patient- and family-advisors engaged, many other roles may emerge, such as the following:

Roles for patient- and family-advisors in medical education

- Participate in focus groups to develop new educational activities.
- Help plan evaluation of educational activities.
- Co-teach educational sessions for medical students or residents.
- Fill positions as home visit coordinators or patient and family coordinators.
- Help plan needs assessments.
- Lead small group discussions with medical students or residents.
- Orient new families who will host home visits.
- Serve as mentors for new patient- and parent-advisors.
- Help plan educational research.
- Edit written reports, drafts of grant proposals, and drafts of articles.
- Write a quarterly summary of patient- and family-advisors' contributions.
- Co-present at conferences and professional meetings.

"The range of advisory roles that families can play is almost limitless. Although many people think of a formal task force or committee when discussing the advisory functions that families perform, the concept can, and should, be more broadly conceived. The term "advisory" should be used to describe any role that enables family members to have direct input and influence on policies, programs, and practices that impact on ...care..."

-Elizabeth Jeppson and Josie Thomas, 1995, *Essential Allies: Families as Advisors*

Gather a Group

It is relatively easy to find a group of people who will talk about their experiences in health care and apply their insights to medical education. People will participate when presented with a question about their doctors about which they have an opinion, or when they sense that those responsible for a medical education program want to hear what they have to say about doctors and patients and the way their relationships affect health care. Most people are interested in the present and future of health care and many want to make a difference if they can.

"It used to be that professionals held all the capacity and patients were seen as passive, helpless and dependent. No more; the new professional role is closer to that of a coach, helping patients be as capable as they can, and stepping in only when their needs exceed their capacity."

-Anthony Suchman, MD, medical educator

People who live with a chronic illness or a disability have a particular interest in the way physicians will interact with patients in the future. They spend a lot of time going to the doctor, and the ways their doctors interact with them, figure out what they need, and help them make health care work in their lives matters to them. They may not know how to articulate physicians' behaviors in terms of competencies for medical education, but they can describe what works well for them. Often, when asked to think about it, they can generate creative ideas for teaching "what works" to medical students and residents. Furthermore, some people who have serious medical needs are highly motivated to help improve care for other people. Participating in medical education may contribute to their sense of meaning or purpose regarding the difficult times they have experienced or it may meet an altruistic need to help someone else. It is therefore relatively easy to find a group of people who have needed medical care for themselves or someone in their family who will eagerly participate in an opportunity to help shape the next generation of physicians.

To find some volunteers who have had experience as patients and families members, ask colleagues if they will ask patients if they would like to share their ideas about medical education. Post recruitment flyers in clinics, hospitals, and a medical school. (See some sample recruitment flyers in the Appendix.) Try to find enough money to provide a small honorarium or reimburse for childcare, transportation, and parking. Then find some faculty colleagues who are willing to listen to the volunteers and begin to plan together.

The Advisory Process

In summary, the process of working with patient- and family-advisors involves these three steps:

1. Develop a clear and focused question relevant to a competency.
2. Convene a focus group of advisors who have had experience with the situation in question.
3. Ask the group to share their perspectives on this question, describe physician behaviors for the competency, and begin to help plan a way to teach the competency.

For example, if you wanted to develop an elective on spirituality in health care, you might convene a group of people who have an interest in this topic and have had some experience as patients. A focus group plan for this group might look like this:

Focus Group: Spirituality in Medicine

PARTICIPANTS:

Parents, patients, and other family members who have an interest in spirituality in healthcare settings

OBJECTIVE:

To gather patient perspectives on spirituality and medicine to inform the development of an elective for the medical school (and possibly the graduate school of nursing)

MATERIALS:

Coffee, muffins, cups, and napkins	Storyboard, index cards, push pins, pens
Tape recorder, tapes	Sign-in sheet

OUTLINE:

15 minutes	1. Welcome and introductions • Purpose of this group • Study consent forms—explanation, sign, collect • Introductions around the group—names, who are your immediate family members? • Permission to tape record
20 minutes	2. Give each participant a chance to respond to the following: • Please share a story from your own experience that illustrates the role of spirituality in your or your family's health care. [focus group leaders go first with an example from their own lives, demonstrating the kind of experience and the appropriate length of time.]

Goals for a patient- and family-advisory group:

a. To incorporate patient and family perspectives in medical education
b. To shape medical students' or residents' practice of medicine to better meet the needs of patients and families

15 minutes	3. Ask the group to think about the following question: How have doctors or nurses interacted with you regarding spirituality? • Give participants time to record on index cards, one comment per card: i. Of the things that doctors and nurses have done in regard to spirituality, which have been helpful? ii. What do you wish they had done differently? • Solicit cards from the group, asking participants to explain each briefly. Ask for the cards in categories. Group on storyboard in two columns, labeled "helpful" and "wish had been done differently."
20 minutes	4. Discuss as a group: How does spirituality play a role for you and your family when you are in healthcare settings? When you are making healthcare decisions?
20 minutes	5. Distribute the following set of questions to the participants. Ask them to consider this question: "What are your reactions to the following questions that a doctor or nurse might ask a patient or family member?" Repeat process with index cards to solicit participants' responses. (questions adapted from Puchalski[2]) • Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress? • What importance does your faith or belief have in your life? Have your beliefs influenced you in how you handle stress? Do you have specific beliefs that might influence your healthcare decisions? • Are you a part of a spiritual or religious community? Is this a support to you and how? Is there a group of people you really love or who are important to you? • What can I (the doctor) do to support you in this area? Is there someone I can call for you? Do you have a certain spiritual practice you would like me to keep in mind?

20 minutes	6. Ask the group to think about the following question: "What suggestions would you have for incorporating teaching about spirituality and medicine in education for medical students or graduate nurses?" • Give participants time to record on index cards, one comment per card: i. Suggestions of teaching approaches. ii. Principles to follow in teaching. • Solicit cards from the group, asking participants to explain each briefly. Ask for the cards in categories. Group on storyboard in themes. • How could I (a doctor or nurse) address these issues in your health care?
10 minutes	7. Wrap up, discuss next steps

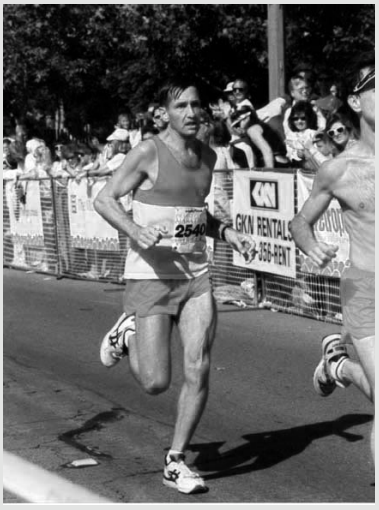
Focus Group Logistics

1. Choose a topic. Sample topics include the following:
   a. Communication.
   b. Establishing rapport and trust.
   c. The medical interview.
   d. Living with chronic illness and developmental disabilities.
   e. Professionalism.
   f. Patient education and health literacy.
   g. Patient adherence to medical treatment.
   h. Shared medical decision-making.
   i. Discharge planning.
2. Write an objective for the group.
3. Develop a focus group facilitation plan.
4. Have specific questions for the group to address.
5. Use story boards, sticky notes, index cards, and flip charts to capture ideas.

"These focus groups then see value in their experiences, worth in their struggles, and hope in the future for others who will travel this path after them."

–Kathy Vestermark,
parent- and patient-advisor

"I enjoy help[ing to shape] our new doctors. It's a great way to educate them about interacting with parents. It's an awesome program."
–a parent-advisor



6. Ask the participants to write behavioral descriptors for medical students, residents, and expert physicians.
7. Generate teaching ideas.
8. Plan a specific teaching session for medical students or residents.
9. Invite some patients and families to co-teach.
10. Get some feedback and revise the teaching plan.

For more information about facilitating focus groups, see a reference such as The Focus Group Kit[3] or involve faculty familiar with focus groups, perhaps from social work, education, or medical psychology.

Create an Open Door

Medical education is a world that has traditionally been directed by professional medical educators with very little input or help from patients or families. Some patients and families may feel hesitant to share their ideas until they are sure that the medical faculty wants to listen. This heightens the importance of the atmosphere we set. It is incumbent upon those who gather a group of advisors and facilitate the discussion with them to create a level playing field. We need to listen with open minds, take notes when the advisors talk, and genuinely look for ways to incorporate their suggestions. When they know we value their opinions, they will quickly share from their hearts about what they need from their doctors and how we might convey this to the next generation of physicians.

What patients and families need to participate as partners in education

1. An open door, knowing their opinions are valued
    - Provide opportunities for collaboration at individual, program, and plan levels.
    - Ask important questions.

- Respond concretely to family concerns and suggestions.

2. Flexibility
    - Arrange times that work for a particular community or group of families.
    - Understand that variable attendance may occur, especially as health needs vary.
3. Logistical support
    - Arrange for childcare or welcome children at meetings.
    - Provide mileage reimbursements or honoraria.
    - Develop job descriptions or role descriptions.
    - Provide background information about topics, but in a way that does not require time-consuming study. These people may spend a significant amount of time meeting their own health needs or those of a family member, which limits the time available to prepare for meetings.
    - Ask specific questions.
    - Offer varied structures and multiple opportunities for providing input.
4. Seeing something good happen for their child or for families overall
    - Choose issues where there is some openness and possibility for success.
    - Make changes.
    - Provide feedback to families about the differences that occur as a result of their participation and recommendations.
    - Remember that making a difference is a powerful motivator.
5. Appreciation
    - Write thank you notes.
    - Create certificates of appreciation.
    - Host occasional luncheons.

"I think the whole session is such a wonderful opportunity. It helps us parents feel like we are making a difference in the medical profession."
–a parent-advisor

Research, Human Subjects Protections, and Institutional Review Boards

Parents and patients are important research collaborators as well. They can help define research questions, provide qualitative data through focus groups and interviews, help write relevant and understandable questions for surveys, and enhance research relevance in other ways. Some special considerations are necessary, however, if focus groups and educational evaluation form part of a research project. Chief among them is informed consent. Sample informed consent documents are provided in the Appendix for two activities: hosting home visits and participating in an advisory group that will contribute to a variety of research activities.

Staff

If your advisory group becomes large, some practical strategies will make it easier to manage. One is to provide orientations for new advisors. Veteran participants can easily meet with new advisors in their homes, provide an overview of the project's activities, and leave a packet of information with contact names and phone numbers and guidelines for hosting home visits and participating as co-teachers in already-established activities. (Sample materials appear in the Appendix.) Veteran participants also often become well-qualified to take over much of the work of scheduling parent- and patient-advisors for focus groups, home visits, and teaching activities. Sample job descriptions are provided in the Appendix for a Patient and Family Coordinator and a Home Visit Coordinator.

Building Relationships in a Medical School

All medical schools have constraints that present some challenges to establishing a patient- and family-advisory group. Faculty members have limited time to develop new educational activities and existing course requirements lead to a full curriculum. Activities developed with parent- and patient-advisors are more easily integrated with existing requirements when they address LCME and ACGME objectives.

Patient- and family-advisory activities enhance curriculum and motivate faculty and students alike. These activities also provide opportunities to bring new faculty partners into teaching and facilitation roles. If you look across the curriculum in your medical school to find opportunities, and look across the faculty to find allies, you will discover a natural fit and rewarding results.

Patient- and family-advisory activities enhance curriculum and motivate faculty and students alike.

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